

BioTrust Community Values Advisory Board Minutes  
Monday, February 4, 2013  
East Lansing, MI

**CVAB Members Present**

*Voting Members*

<input type="checkbox"/> Linda Burghardt	<input checked="" type="checkbox"/> Tedra Jackson	<input checked="" type="checkbox"/> Vicki Rakowski	<input checked="" type="checkbox"/> Amy Zaagman
<input checked="" type="checkbox"/> Denise Chrysler	<input type="checkbox"/> Joyce Kornbluh	<input checked="" type="checkbox"/> Stephen Rapundalo	
<input type="checkbox"/> Alesia Grinstead	<input type="checkbox"/> Neil MacVicar	<input checked="" type="checkbox"/> Tina Reynolds	<b>CVAB Designees</b>
<input type="checkbox"/> Kara Hamilton	<input type="checkbox"/> Mary Lou Mason	<input type="checkbox"/> Viet Tran	<input checked="" type="checkbox"/> John Roy Castillo
<input checked="" type="checkbox"/> Rosalyn Beene Harris	<input type="checkbox"/> Tressa Orthmeyer	<input type="checkbox"/> Rita Walters	

*Community Attendees:* Ella Greene-Moton, Meta Kreiner, Ann Mongoven, Elizabeth Taylor, Yvonne Lewis

*MDCH Staff:* Janice Bach, Kidist Dimore, Carrie Langbo

**1. Welcome and Introductions... Tedra Jackson**

- T. Jackson welcomed board members and guests and introductions were made.

**2. Review of 10.1.12 Minutes**

- T. Jackson entertained a motion to approve the 12/3/12 minutes. V. Rakowski supported the motion. All members approved.

**3. MDCH Follow-up Report..Carrie Langbo**

- CVAB Meeting Minutes Posted On-line: Request from community to place CVAB meeting minutes on-line. No objections to fill this request were voiced. Beginning with 2013 CVAB meetings, CVAB meeting minutes will be placed on BioTrust website once approved at subsequent CVAB meeting.
- CVAB Membership Renewals: All 2011-2012 member organizations were invited to renew membership. 11 out of 16 organizations accepted renewal with same representatives, 4 organizations will remain on the CVAB with new representatives, and 1 organization has yet to respond. MDCH is still working with MOSES to determine their interest in filling the interdenominational faith-based organization seat. Discussion will ensue today regarding 3 additional seats.
- CVAB Vice-Chair: Two CVAB members nominated but respectfully declined. Discussion ensued regarding vice-chair term, transition to chair and necessity of position. Unless CVAB member steps forward for nomination, the issue will be tabled for future meetings. Immediate past chair will assist current chair when/if necessary.
- Consent Update: Rates continue to remain consistent with past data. During December 2012, 89% consent forms were returned of which 64% were signed, 21.9% were marked refused, and 14.2% were blank. After a year of outreach and education, one birthing hospital reduced its rate of returning blank forms from 90% to 46%. Approximately 59% of the newborn population is in the consented pool of BioTrust samples. Dr. Michelle Lewis, researcher from Johns Hopkins University, received a grant from the Robert Wood Johnson Foundation to assess whether MDCH's consent policy maintains a robust sample population for health research. The study will also assess whether the consent model ensures the integrity of newborn screening and informed decision-making by parents.

- Dried Blood Spot Research Report: Four proposals have been submitted to date in 2013 with 2 approved and 2 still under review. The cause of congenital hearing loss is assessed in one study and advancing the NBS platform with chip technology is assessed in the second study. The DBS community report is completed and will be posted on the BioTrust website pending MDCH communications approval.
- BioTrust General Updates: BioTrust manuscript accepted for publication in Public Health Reports. During February, a BioTrust informational briefing meeting is scheduled with MDCH Director Jim Haveman and a Scientific Advisory Board Task Force meeting will occur. S. Rapundalo will take part in the Task Force meeting and updates from both meetings will be provided in May. BioTrust website is being revised within the limits of the MDCH platform. If anyone has specific recommendations please contact Carrie. Attempts are being made to schedule the September CVAB meeting in Detroit at the MNB.

#### **4. MDCH IRB Update...*Tedra Jackson***

- T. Jackson informed the board that MDCH IRB granted approval of the new BioTrust consent brochure and form. Current forms and booklets will be utilized until the inventory is depleted. The goal is for new material to be in circulation by May 2013.

#### **5. 2013 CVAB Priorities**

- Student Seat: Discussion ensued regarding seating a “student” v. “advisor of student organization”, upper v. lower classman, type of student organization to ensure interest and prolonged commitment to CVAB seat, and selection process. Decision: contact student section, chair, of the Michigan chapter of the American Public Health Association to determine interest.
- Member at Large Seat: Two seats will now be designated CVAB Member At Large. Application form and selection committee review sheets were discussed and revised. Application form will be distributed to CVAB members, community members, Ann Mongoven (MSU Deliberative Jurors) and University of Michigan Life Sciences and Society researchers for circulation. MDCH will tweet and post Facebook notices about the application, and the form will be found on the BioTrust website. Applications are due March 15, 2013. The CVAB selection committee consisting of V. Rakowski, T. Jackson, T. Reynolds, D. Chrysler and J. Castillo, will then select and rank the top 5 candidates. References will be checked and MDCH will invite two individuals for CVAB membership. CVAB operating policy and procedures will be revised to incorporate the additional member seats and selection process.

#### **6. Public Comments**

- Ms. Greene-Moten, on behalf of her community partners, appreciates the time to create the Member at Large application process. Ms. Taylor concurs. Reminder was made to ensure all present speak clearly so those participating via telephone can better participate. Dr. Mongoven introduced a new pilot project to reach out to parent groups regarding the BioTrust. An initial contact flyer was shared and electronic version will be distributed with the minutes.